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¹Kigan Wycliffe, ²Dr. Erick Rosana Masese

^{1,2}Department of Sociology and Psychology, Moi University, Kenya

¹kiganwycliffe@yahoo.com ²menr2002@yahoo.com

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Knowledge and Social Construction of Epilepsy and its Treatment among Households of Vihiga County, Kenya

¹Kigan Wycliffe ²Dr. Erick Rosana Masese

^{1,2} Department of Sociology and Psychology, Moi University, Kenya

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January-June 2016. The study sort to understand knowledge on causes and treatment modalities of epilepsy among people living in Vihiga County. A sample of 121 participants was randomly selected from 121 households that were selected through stratified proportionate sampling techniques.

Results: Thirty five (35%) defined epilepsy by describing what happens during an epileptic fit. 30% defined epilepsy by giving signs and symptoms of the condition, 24% explained epilepsy by explaining cause of the condition while 10% explained using perception: Causes; Respondents gave varied responses on causes for epilepsy, they included, curse, breaking a taboo, heredity, acute illness such as Malaria and complications from physical injury to the brain: Treatment; 50.8% said epilepsy can be treated using anti-epileptic medicine. 11.5% said herbal medication could heal epilepsy, 6% said eating cooked dog meat could heal epilepsy, 20% said rituals and animal sacrifices could heal epilepsy while 1% said epilepsy can be resolved by killing the person who is suffering epilepsy.

Conclusion: Though signs and symptoms of epilepsy are well known, there is knowledge deficit on causes and treatment of epilepsy.

Introduction

Over 51 million people suffer epilepsy worldwide (WHO, 2015). This health condition has been identified as a health priority by the World Bank because of its' high psychosocial morbidity (Mung'ala-Odera et al. 2008). The focus on psychosocial aspect of epilepsy is important because health and illness cannot be viewed separate from the social and cultural context in which human being live. Social context thus, become an important factor in determining health outcomes. Jacoby (1992) describes epilepsy as both a medical diagnosis and a social label. By social label the Jacoby means that there are several psychosocial problems accompanying the disease thus, its impact on a person's everyday-life can be significant.

Adequate knowledge on epilepsy as an illness can reduce stigma attached to the condition. The International League against Epilepsy (ILAE) classifies epilepsy syndromes as either idiopathic or symptomatic. Idiopathic etiology is whereby epilepsy develops in an otherwise normal child while symptomatic is whereby epilepsy occurs in the setting of a known or suspected abnormality of the central nervous system. Epilepsy can be observed at any age. However, it is frequently seen at early ages. Most epileptic persons have their first epilepsy seizure before age 20. Epilepsy affects 3-5% of people during their developmental periods (Baum et al. 2007). Epilepsy is characterized by its episodic and chronic nature. The seizures usually produce brief periods of disruption, which include loss of consciousness, bodily distortion, injuries, unusual and often frightening psychological experiences as well as

Abstract

Background: Epilepsy is a medical condition with serious social ramification. People living with epilepsy experience lowered quality of live and altered self-esteem as a result of stigma attached to their condition. This stigma may be attributed to knowledge deficit and different social meaning on epilepsy among populations. This study sort to assess knowledge and social construction of epilepsy and its treatment modalities among households in Vihiga County of Kenya.

Method: A survey study was carried between

urinary and bowel incontinence. The unpredictability of seizure recurrence is a constant threat to the patient with epilepsy and his or her family.

Apart from the episodic seizures, there are many other ever-present factors: social, psychological, behavioral, educational, cultural and so forth-which affect the lives of children with epilepsy, their families and their close social networks. These factors vary considerably from one person to the next, but have a significant impact on the daily quality of life in every affected individual (Ronen et al. 2003). Epilepsy is a complex neurological condition with many possible co-morbid features. For example, a common co-morbid with this condition is Learning Disorders (LD). LD are more common in children with epilepsy than in the general population. LD are defined as disorders that interfere with academic performance or with daily activities that require reading, writing or mathematical skills in subjects with a normal intelligence quotient (IQ). The prevalence of LD in the general population has been found to be 2-10%, and reading disorders are the most frequent subtype. Many childhood epilepsy syndromes are readily treated and have an excellent prognosis. Accurate and early diagnosis may ameliorate the psychosocial impact of these disorders on children and their families.

To be epileptic means being exposed to the fear of having attacks, being at a disadvantage in terms of work and personal relationships, being open to prejudice, this exists both in the lay public and in the medical and nursing professionals. Unpredictability in connection with epilepsy is a source of fear and insecurity, giving the patient a constant feeling of being under threat. Fear of social exposure of fits and feelings of disgrace often lead to social isolation. Mitan, (1983) observes that 50 to 75 per cent of persons with epilepsy spent almost all their time at home. Many epileptic patients develop an extreme dependence upon their relatives, and this dependence interferes with the development of social skills. Public ignorance and fear of the unknown is another important source for the epileptic patients' problems. It is frightening to see a person having an epileptic attack, losing control of himself, and the simplest way to prevent such fear is to avoid the person with epilepsy.

The consequence is even more social isolation and difficulty with employment for the patient as well. (WHO, 2004) estimates that 80% of people suffering from epilepsy around the globe reside in developing world such as Africa. According to Forsgren et al (2005); Theodore et al (2006) the lifetime prevalence

rate for epilepsy ranges from 3.5 to 10.7 per 1,000 person-years in developed countries. The lifetime prevalence rates for active epilepsy varied from 1.5 to 14 per 1,000 person-years in Asia (Mac et al., 2007), from 5.1 to 57.0 per 1,000 person-years in Latin America (Burneo et al., 2005), and from 5.2 to 74.4 per 1,000 person-years in sub-Saharan Africa (Preux&Druet-Cabanac, 2005).

It is uncertain whether these broad variations between environmental regions are attributable to varying definitions of epilepsy or whether they are related to geographically relevant risk factors such as poverty, illiteracy, poor sanitation, inaccessibility of medical care, birth-related trauma or cerebral cysticercosis (de Bittencourt et al. 1996). Cultural interpretation contributes to exclude epileptic persons from the educational and productive fields, aggravating the burden they face and favoring a treatment gap estimated to 80% (WHO, 2004). Treatment gap is the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage (Meinardi et al. 2001).

Since ancient times social structures have been a hindrance to quality of life to people living with epilepsy, for example, in the 2nd and 3rd century's physicians and philosophers associated epilepsy with the lunar phases and this bred the misunderstanding that epilepsy was a form of lunacy (Chadwick, 1997). Discriminatory laws are recorded as far back as 2000 BC, in the Babylonian code of Hammurabi, Fernandes et al (2011). Anti-marriage laws for people with epilepsy were in place in Europe and U.S as recent as late 60's-early 80's. The Eugenics Movement legitimized some 60,000 sterilizations of PWE in the United States between 1907 and 1964. Perceptions on epilepsy are often negative, which compromises attitudes and impairs the patient's quality of life, reinforcing the stigma and thus closing a vicious circle, Fernandes et al. (2011) and (Austin & de Boer, 1997). Understanding culturally specific beliefs about the causes and prognosis of conditions of ill-health will help determine how the condition can be managed both individually and collectively and how the stigma attached to it can be eliminated. This study sought to understand the beliefs and causal explanation of epilepsy among the households of Vihiga County in Kenya. It is through the understanding of how people perceive epilepsy that we may be in a position to understand how people living with epilepsy make

meaning of their illness amidst society response to epilepsy.

Research Methodology

The study aimed to explore households' knowledge on epilepsy and its treatment in Vihiga County. Structured interviews with 121 respondents using a 31 item questionnaire with close and open ended questionnaire. A sample of 121 participants were selected for the study. From a sampling frame of 2000 household's a proportionate stratified sampling was done to arrive at sample size of each strata. The Kth number was used to select a household. One member of the selected household was interviewed. In this population-based survey, the researchers interviewed 121 people. The results showed that people have an understanding of what epilepsy as medically defined they but have knowledge deficit on causality of the condition as defined by medicine. Nearly half of the respondents proposed medical intervention while the remaining suggested traditional approach. There were 121 respondents in the study. Majority of the respondents (42.1%) were aged between 15 and 35. There were 41.3% male and 58.7% females respondents. 52.1% were married, while 26.4% were single. 15.4% had no formal education, 33.9% had attended schooling up to secondary school. 36% were employed, 20% were self-employed, 43% were unemployed.

Knowledge on epilepsy.

Thirty five (35%) defined epilepsy by describing what happens during an epileptic fit. For example, a respondent said "*epilepsy is a condition whereby, if you are affected, you fall down and urinate in your cloth*". Close to 30% defined epilepsy by giving signs and symptoms of the condition, such as, smirked lips and body wounds such as burns wounds. 24% explained epilepsy by giving causation, such as "*it is a disease caused by witchcraft*" while 10% explained using perception, such as "*it is a sickness that is feared by many people because it is contagious*". 71.3% of the respondents had witnessed someone with epilepsy have a seizure.

Respondents were asked if they could identify any signs that one was about to have an epileptic seizure. Thirty four (34%) of the respondents described warning signs of an impending epileptic seizure by way of body signs an epileptic had as just before a seizure. Body signs identified included lack of concentration, uneasiness and tension. 30% said they could tell one is about to have an epileptic fit from his or her behavior such as shouting or having a loud cry. 15% said they

could tell by the look on the epileptic face such as a daze or an angry look.

Causes of epilepsy: Respondents gave varied responses as causes for epilepsy; 9.8% said epilepsy is as a result of a curse, 12.3% said epilepsy is caused by breaking a taboo, heredity, 64.8 % said epilepsy can be caused by acute illness such as Malaria and complications from physical injury to the brain. 84.4 % agreed that epilepsy is inherited while 12.3 % disagreed. 12.3% said one can get epilepsy by sharing food with an epileptic but 85.2% disagreed.

Treatment of epilepsy

Fifty percent 50.8% said epilepsy can be treated using anti-epileptic medicine. 11.5% said herbal medication could heal epilepsy, 6% said eating cooked dog meat could heal epilepsy, 20% said rituals and animal sacrifices could heal epilepsy while 1% said epilepsy can be rid off by killing the person who is suffering epilepsy.

From the above findings, the study describes knowledge on causes of Epilepsy and its treatment in a sample of respondents drawn from household in Vihiga County of the Republic of Kenya. No research on knowledge and attitude on epilepsy has previously been done in Vihiga. This study benefited from a robust sampling strategy and a considerable amount of fieldwork of 121 interviews. The sample included members of households with a wide from a range of different educational, professional, and marital, religions, socioeconomic backgrounds and ages in an attempt to capture the diversity of views and beliefs. A weakness of the study is the over-representation of youth and young people in the sample. However, this is a true reflection of the Kenya national population. In addition, the sample was limited to local people from one geographical area in Kenya. However, this study findings can be a pointer to the need to carry out a large survey. The focus of the study was people's beliefs on causes and treatment of epilepsy. Results from this study are likely to be relevant to beliefs about the causes of, and treatments for, other illnesses and conditions that have attracted stigma.

Results on demographic show a population majorly composed of youth and young people, majority of who were unemployed. This is a reflection of Kenya population demographics. Kenyan population is composed of 35% of youth and 43 % children, with high unemployment rate, (KNBS, 2015). General characteristics of the population in the African Region include: an age distribution in favour of youth,

predominance of poverty, and a majority of people living in rural areas. About 36% of Africans live in cities. Most of these population live in the suburbs in poor conditions characterized by overcrowding, poor water supply and bad sanitation.

Consequently, there is a high prevalence of communicable diseases such as malaria, meningitis, cysticercosis and tuberculosis, which are frequent causes of epilepsy, World Health Organization (2004). 15.4% had no formal education, 33.9% had attended schooling up to secondary school. The mean adult illiteracy rate in the African Region is about 38.5%. The rate of illiteracy is an important factor to consider when designing campaigns programs to disseminate correct information epilepsy. Correct information concerning epilepsy is important factor for changing the perception of pre-established prejudices and beliefs and can contribute to minimizing the stigma perception within society.

WHO, statistics 1988-2003 show the prevalence of epilepsy in Kenya to be 18.20/1000. This prevalence applied to Kenya population of 40 million will translate to about 728,000 people living with epilepsy. This means that about 2% of the Kenyan population has epilepsy. This implies majority of cases of epilepsy are young because Kenya population is dominantly young. Abigail et al (2012) observes that, the prevalence of active epilepsy peaks in the 20-29 age group (young people) at 11.5/1000. High prevalence of epilepsy in young people has potential negative consequences for both workforce and community structures, Abigail et al (2012).

Knowledge on Epilepsy and Its Causes

The researcher was interested in understanding how people define epilepsy and their knowledge on causes of epilepsy. Open ended questions were posed on what epilepsy is and what causes it. The researcher read through the description given and created categories that are discussed below.

Defining epilepsy: Four categories emerged on how the respondents defined epilepsy. Thirty five (35%) defined epilepsy by describing what happens during an epileptic fit. For example, Respondent J: *"epilepsy is a condition whereby, if you are affected, you fall down and urinate in your cloth"*. Epilepsy is an umbrella term for different seizures. It is evident by recurrent, typically unprovoked epileptic seizures (Guberman and Bruni, 1999). Seizures are transient episodes 'of neurological dysfunction brought about by abnormal, synchronous and excessive discharges of cerebral

neurons' (Oxbury, Polkey, and Duchowny, 2000). Epilepsy is characterized by seizures and unconsciousness accompanied by urine incontinence and frothing in the mouth. This are typical explanation given by respondents like Respondent J above. Many definitions of epilepsy focus on the unprovoked and recurrent nature of seizures.

We can thus conclude that respondents are knowledgeable on the diagnosis of epilepsy. Jacoby et al (1996) study on interpersonal and family relationship found that the more seizures someone had the less likely they were to be married and the more likely they were to not be in a relationship or to be divorced or separated. These findings have been reflected in other studies which highlight disparities in marital status in people with epilepsy in relation to control groups (Arnston, Drodge, Norton & Murray, 1986; Collings, 1990).

Thirty percent (30%) of the respondents defined epilepsy by giving signs and symptoms of the condition, such as, smirked lips and body wounds such as burns wounds. Person with epilepsy are prone to injuries occasioned by epileptic seizer. Seizer are uncertain and people who live with epilepsy are unaware on when a seizer will occur. On occasion the seizer may occur when the person is in a potentially dangerous situation such near fire place, place with sharp object and pools of water. Fisher et al. (2000) found that the fear of having a seizure and the uncertainty associated with epilepsy were reported as the most problematic features of having the condition. Seizers have direct and indirect link to social stigma. Direct link is that discrimination and misconceptions emerge from the nature of seizers that are usually violent and frightening. Indirect link is because of injuries sustained during an epileptic seizer such as gross body deformity from burns and scarred wounds. 34% of the respondents described warning signs of an impending epileptic seizer by way of body signs a person with epilepsy has just before a seizer attack. Body signs identified included lack of concentration, uneasiness and tension. 30% said they could tell one is about to have an epileptic fit from his or her behavior while 15% said they could tell by the look of the epileptic.

Twenty four percent (24%) explained epilepsy by giving causation, such as *"it is a disease caused by witchcraft"* and *it is a disease cause by breaking a taboo*. Respondents were asked an open ended question on the cause of epilepsy. Respondents gave varied responds as causes for epilepsy, they included,

witchcraft, curse, breaking a taboo, heredity, acute illness such as Malaria and complications from physical injury to the brain. The common name for Epilepsy in Vihiga County is *idulumi*. It is pronounced *I'ndu'rumi*. The word *Indurumi* is derogative. The other name commonly used for epilepsy is a Swahili word *Kifafa*. The term *Kifafa* is more used by the younger population. Most young people speak in Kiswahili than the local languages spoken in Vihiga County. Kiswahili is a national language in Kenya and East Africa. 9.8% said epilepsy is as a result of a curse, 12.3% said epilepsy is caused by breaking a taboo, heredity, 64.8% said epilepsy can be caused by acute illness such as Malaria and complications from physical injury to the brain. 84.4% agreed that epilepsy is inherited while 12.3% disagreed. 12.3% said one can get epilepsy by sharing food with an epileptic but 85.2% disagreed.

Medically, epilepsy is a brain disorder characterized by recurrent seizures during which some people lose consciousness and control of bowel and bladder function (WHO, 2009). The seizures are as a result of sudden, usually brief, bursts of large electrical discharges in a group of brain cells (Khalid & Aslam, 2011). Epilepsy can be caused by almost any form of cerebral pathology such as birth trauma, head injury, infection, tumours, congenital defects, and exposure to toxic agents, degenerative disorders and cerebrovascular disease. Head injury, congenital CNS abnormality, tumours, vascular and metabolic disorders are increasingly being reported as causes of epilepsy in adults in the African Region (Ruberti, 1986; Matuja, 1989).

Beliefs about health and illness affect people's decisions regarding their choice of treatments. Prejudice from people who believe that epilepsy is contagious is widespread in society. Prejudice underlies stigma associated to epilepsy. Stigma and exclusion are common features of epilepsy and a major contributor to the burden associated with the condition. Stigma alters self-esteem of people with epilepsy and their families. Reducing stigma of epilepsy is key to improving individual's life opportunities and the overall quality of life.

In this study, majority of those who attributed epilepsy to witchcraft were the older respondents. History of Epilepsy is surrounded by myths and mystery. These findings are in concurrence with Goffman (1963) who noted that people suffering from epilepsy have been seen as possessing 'an undesired differentness'. Though known as 'the sacred disease' to the ancient Greeks (Temkin, 1971), epilepsy has more often been

associated with negative and pejorative imagery. Jacoby and Baker, (2000) observe that across time and different cultures, epilepsy has and had been variously viewed as the outcome of sin, as the product of demonic possession and/or a form of madness and consequently, as a condition to be feared and rejected. Ten percent (10%) of the respondents explained using perception, such as "*it is a sickness that is feared by many people because it is contagious*".

Response to and Treatment of epilepsy

Seventy one percent (71%) of participants in the study had witnessed an epileptic seizure. Twelve percent (12.3%) of the respondents who had witnessed the seizure, ran away on witnessing a fit, while, 17.2% did not do anything, 38% placed the victim under a shade while 17% reported putting a spoon in the epileptic mouth. 49.2% said epilepsy was contagious. 84.4% said epilepsy is hereditary. 59% said epilepsy was preventable. 37% said early medication could prevent epilepsy while 27.9% said epilepsy can be prevented by avoiding contact with fluid such as saliva and urine from the epileptic. 50.8% said epilepsy can be treated using anti-epileptic medicine. 11.5% said herbal medication could heal epilepsy, 6% said eating cooked dog meat could heal epilepsy, 20% said rituals and animal sacrifices could heal epilepsy while 1% said epilepsy can be rid-off by killing the person who is suffering from epilepsy.

Epilepsy can effectively be controlled by modern treatment of Anti-epileptic medication. However, this is contrary to the general belief because eighty percent (80%) of people with epilepsy who reside in Africa do not receive modern treatment, or are not even identified. It is significant time elapses between initial development of epilepsy and the time treatment is sought. This may have implications for the outcome of epilepsy. Oscillating between contemporary medical management and traditional management of epilepsy may be an indicator of misconception on causality of epilepsy. Traditional medicine such as Ayurveda in India, Kampo medicine in Japan and herbal medicine in China and Africa has continued to play a significant role in the treatment of Epilepsy. Misconceptions on epilepsy, beliefs, poor infrastructure, and insufficient availability of drugs and scarcity of trained medical personnel have been cited as relevant factors for large percentage of people living with epilepsy accessing treatment. Improved outcome of epilepsy can be realized through accessibility, availability and follow-up of the control of the seizures with anti-epileptic

drugs and the cure of the underlying aetiology if possible.

Conclusions

There is knowledge deficit on causes of epilepsy in Vihiga County. The implication of the knowledge deficit is that epilepsy has been made a social problem problematized by its social and symbolic meanings in everyday life. To a great extent a number of psychosocial outcomes are determined by other people's attitudes and reactions towards people with epilepsy. In this study, respondent's knowledge deficit

on epilepsy has the potential of negatively impacting on persons living with epilepsy. Correct information concerning epilepsy is important factor for changing the attitudes and perception of pre-established prejudices and beliefs, and can contribute to minimizing the stigma perception within society. In view of this, it is necessary that destigmatization campaigns are mounted on a repeated basis, to correct information and improve quality lives of those living or affected by epilepsy. Health professionals need to be aware of beliefs of the catchment population they treat if meaningful health outcomes are to be realized.

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